LEGISLATIVE BREAKFAST

April 11, 2014

Direct Support Professionals:
The Unsung Heroes in Our Community

The State of California accepts a responsibility for persons with developmental disabilities and an obligation to them which it must discharge. An array of services and supports should be established which is sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, and at each stage of life and to support their integration into the mainstream life of the community. It is the intent of the Legislature that agencies serving persons with developmental disabilities shall produce evidence that their services have resulted in consumer or family empowerment and in more independent, productive, and normal lives for the persons served.

(Welfare and Institutions Code §4501)

NORTH LOS ANGELES COUNTY REGIONAL CENTER

Contents

California's Promise to its Most Vulnerable Citizens is at Risk	3
Rate Table of Community Reimbursement for Services and Supports	5
Challenges to Sustaining California's Developmental Disability Services System, UCLA Center for Health Policy Research, March 2011	7
Tierra del Sol Board Member Karren McClenahan	16
The Adult Skills Center (TASC)Board Member Nick Leone	18
New Horizons' Direct Support Professional Sarah Macon	20
Economic Policy Institute's Family Budget	21
Entry Level Wage Comparison	22
Voting Population	23
Other Resources	24
Sample Letter That You Can Send To Legislators	25
Legislators Serving NLACRC's Catchment Area 2014	26
CA STATE SENATORS	26
U.S. SENATORS	27
CA ASSEMBLY MEMBERS	27
CA CONGRESSIONAL REPRESENTATIVES	29
L.A. CITY COUNCIL	30
L.A. COUNTY BOARD OF SUPERVISORS	31
LOS ANGELES MAYOR	32
CA GOVERNOR	32
UNITED STATES PRESIDENT	32
Acknowledgments	33

California's Promise to its Most Vulnerable Citizens is at Risk

There are nearly **300,000** people in California who where born with devastating disabilities. Referred to as "developmental disabilities," they are present at birth or occur in early childhood. They interrupt the normal developmental process and they are life-long. These disabilities include intellectual disabilities, autism, cerebral palsy, uncontrolled seizure disorders, and other disabilities that were once lumped together with the unfortunate term "mental retardation." There are no cures for these disabilities.

Until 1971, California law and public policy called for life long institutionalization in large publicly operated "developmental centers" as the principle means of care for people with developmental disabilities. In 1971, Governor Ronald Reagan signed the Lanterman Mental Retardation Services Act into law. It created and funded a system of community services to provide care and treatment for people within their families and communities. The Lanterman Act called for the State, through its regional centers, to establish contracts with and fund local, community-based organizations, to be directly responsible for providing direct services to people with developmental disabilities.

These community organizations are responsible for developing and operating residential and day programs to meet the health, welfare, and support needs of Californians with developmental disabilities. Each local community organization is responsible for recruiting, employing, training, and supervising men and women who serve as direct support professionals and managers of these services. Essentially the Lanterman Act mandated California's transition from a State operated institutional safety net to a community-based safety net comprised of local men and women employed by local community organizations to serve and support Californians with developmental disabilities.

Under the Lanterman Act, services became available in local communities throughout California, helping people with developmental disabilities learn to care for themselves, gain greater independence and, in many cases, to become productively employed. The community-based service model was so successful that California's developmental center population declined from its 1971 high of over **15,000** to its current level of less than **1,310** even as our State population has more than doubled.

Thanks to the Lanterman Act and the network of community-based services it created, California has effectively ended the era of institutionalization for its citizens with developmental disabilities. Not only has the Lanterman Act created a vastly more humane life for hundreds of thousands of people, but it has done so at a remarkable savings in public funds compared to institutionalization. The Lanterman Act stands as one of California's most outstanding public policy achievements.

But now California's system of care is in grave danger.

Though the law guarantees the availability of services and supports to people with developmental disabilities, the law did not establish a mechanism to establish and maintain levels of funding sufficient to sustain the statutory commitments to care and support for people living in the community with these life-long disabilities. It is left to the Governor and State Legislature each year to appropriate sufficient funding to sustain the community-based system of care.

California's Promise to its Most Vulnerable Citizens is at Risk

Because there is no provision in law for the State to assess its reimbursement rates to service providers, compare them to actual economic factors and make adjustments as needed, the Legislature and Administration have not had the benefit of the critical information they need to evaluate the annual impact of their funding decisions to the Lanterman Act safety net. (Please see accompanying UCLA Public Policy Brief.)

While the economic history of California since 1971 has been highly volatile, one area has remained distressingly flat over this period – the rates of reimbursements paid to the State's service providing organizations. The accompanying rate history documents more than 20 years of frozen rates, rate cuts and infrequent emergency infusions to accommodate State minimum wage increases. The chart compares California's rate adjustment history with the Consumer Price Index (CPI) over this period.

The rate history versus CPI actually understates the true losses of funding against true costs because service organizations are primarily workforce employers and as such they have borne the burden of increasing health care costs, workers compensation costs, and other employer expenses that out pace consumer price pressures.

How has the State's basic human service safety net for its most vulnerable citizens sustained itself with reimbursement rates that have fallen more than 50% below true costs? The most direct answer is the wage structure found across California for its direct service professional workforce. Comprising more than 80% of the budgets of community service providing organizations, frozen reimbursements have meant frozen wages and often reductions in benefits and cost transfers to employees as health care costs have increased. The true face of California's safety net is now a poverty wage workforce comprised of dedicated men and women working two and three jobs to make ends meet with no hope for raises or an improved economic outlook. It is a workforce on the edge of collapse. California's safety net is also characterized by its community organizations struggling with unacceptably high turnover and vacancy rates in all critical positions. High quality, gifted employees are leaving for higher wages in fast food and retail chain stores. The strains on the community workforce and the organizations that employ and support them are accelerating. The alarming fact is that, just as California is intentionally ending the era of its institutional safety net, it is unintentionally destroying its community based human safety net through neglect of its workforce.

This year, we must prevent the further erosion of the community safety net with a very modest rate increase to community service providers of 5% while we begin the important work of creating an economically sustainable safety net for the future of Californian's with developmental disabilities.

Californians do believe that government plays a role in meeting the safety net needs of its most vulnerable citizens. We can fulfill this public responsibility, responsibly, in partnership with the Legislature and Administration.

Rate Table of Community Reimbursement for Services and Supports

DEPARTMENT OF DEVELOPMENTAL SERVICES - FACT SHEET

UPDATED BY THE CALIFORNIA DISABILITY SERVICES ASSOCIATION (formerly CRA)

COMMUNITY REIMBURSEMENT FOR SERVICES AND SUPPORTS

The table below is based on a DDS publication through 2000/2001, the current figures are based on DDS rate publications after that period.

The following table compares funding adjustments and Consumer Price Index (CPI) increases. "Gap" is a rate adjustment based on the historic allowable costs for service providers as submitted to the Department every two years, with highest allowable rate set at 80% of the highest submitted rate. "Min. wage" indicates a pass through for mandated minimum wage increases to those rates set at minimum wage.

Starting in 2004/2005 employment programs previously run by the Department of Rehabilitation have moved to the Department of Developmental Services these programs have been added to the table.

Fiscal Year 1	Day Program	Residential	In-Home Respite	Supported Living 2	Supported Employment 3	Work Activity Program	CPI 4
1987/88	0	0	0	not applicable	0	0	4.20%
1988/89	0	0	0	not applicable	0	0	4.90%
1989/90	0	0	0	not applicable	0	0	5.00%
1990/91	0	0	0	not applicable	0	0	5.30%
1991/92	Gap	0	0	not applicable	0	0	3.60%
1992/93	0	0	0	not applicable	0	Gap	3.20%
1993/94	0	0	0	not applicable	0	0	1.80%
1994/95	0	0	0	not applicable	0	Gap funded less 12% Reduction in Rate	1.70%
1995/96	0	0	0	0	0	0	1.40%
1996/97	Min. wage	Min. wage +3%	0	0	0	Gap	2.30%
1997/98	Min. wage	Min. wage +3%	Min. wage	0	0	0	2.90%

Rate Table of Community Reimbursement for Services and Supports

Fiscal Year 1	Day Program	Residential	In-Home Respite	Supported Living 2	Supported Employment 3	Work Activity Program	CPI 4
1998/99	Gap	12.30%	Gap	5%	0	0	2.50%
1999/00	0	12.80%	0	0	0	0	3.00%
2000/01	Wage/benefits 10% Admin 5%	3%	Wage/benefits 10% Admin 5%	Wage/benefits 10% Admin 5%	3%	Wage/ben-efits 1.6%	3.30%
2001/02	0	0	0	0	0	0	1.50%
2002/03	0	0	0	0	0	0	2.40%
2003/04	0	0	0	0	2.5% reduction in rate	5% Reduction in Rate	3.50%
2004/05	0	0	0	0	0	0	2.60%
2005/06	0	0	0	0	0	0	2%
2006/07	3%*	3%*	3%*	3%	24%	3%*	2.10%
2007/08	Min. wage	Min. wage	Min. wage	0	0	0	2.50%
2008/09	0	0	0	0	-10%	0	3.70%
2009/10* thru 2011	(-)3%	(-)3%	(-)3%	(-)3%	-10%	-3%	
2009/10	(-)3%	(-)3%	(-)3%	(-)3%	-10%	-3%	1.00%
2010/11	-4.25%	-4.25%	-4.25%	-4.25%	-10%	-4.25%	2.00%
2011/12	-4.25%	-4.25%	-4.25%	-4.25%	-10%	-4.25%	2.80%
2012-13	-1.25	-1.25	-1.25	-1.25%	-10%	-1.25%	1.70%
2013-14	rate restored to 2008 level	rate restored to 2008 level	rate restored to 2008 level	rate restored to 2008 level	-10%	rate restored to 2008 level	2.40%
Totals	**10 -13%**	**37%**	**10 -13%**	**7-10%**	**19.50%**	**-0.40%**	**73.2%CPI**

Footnotes;
1. The current formal freeze started in FY 2002/03
2. Regulations for Supported Living Service were promulgated in 1995
3. Cost neutral restructuring of rate occurred in FY 1998/99, SE rates are a flat rate paid regardless of location.
4 Source: U.S. Department of Labor, Bureau of Labor Statistics
*In 2006, selected programs in some categories were eligible for an additional 3.86% rate increase to raise staff wages.
**References to minimum wage involve increases to some programs only to raise minimum wage to staff below the threshhold

Challenges to Sustaining California's Developmental Disability Services System, UCLA Center for Health Policy Research, March 2011

UCLA CENTER FOR HEALTH POLICY RESEARCH
March 2011
POLICY NOTE

Challenges to Sustaining California's Developmental Disability Services System

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SUMMARY: California's developmental disability services system is currently facing severe budget reductions as part of Governor Brown's efforts to close the state's budget gap. For more than a decade, guaranteeing adequate funding for these services has been challenged both by a dramatic increase in the number of individuals eligible for these services and by limited resources, rate freezes, and inadequate transparency in resource allocation. These factors threaten the financial solvency of service providers, potentially resulting in decreased access to high-quality care and increasing the cost of care for the state. As the only state in the nation that has established an entitlement for developmental disability services, California must pursue multiple strategies in order to meet the goals of this entitlement and to ensure both adequate and equitable access to high-quality and cost-effective services. This policy note discusses the background of California's developmental disability services and identifies the challenges facing this system. It recommends that the state adjust frozen rates for services, adopt equitable and transparent vendor payment systems, and maximize the efficiency of the current system of service provision, among other policy solutions.

Background

The statutory framework for provision of services to individuals with developmental disabilities in California was established in 1969 by the *Lanterman Developmental Disabilities Services Act* and its later amendments ("The Lanterman Act," Welf. & Inst. Code §4500, et seq.). This bill defines a basic right of individuals with developmental disabilities to receive, and a corresponding obligation of the state to provide, regional community-based services that "maximize opportunities and choices in living, working, learning, and recreating in the community" (Welf. & Inst. Code §4640.7).[1] Services for individuals with developmental disabilities are an entitlement in California and are intended to minimize institutionalization and enable independent living within the least restrictive environment possible (Welf. & Inst. Code §4502).

Services can be generally categorized into three core types: residential care, community programs, and transportation services.[2] Community programs provide a variety of services, including day programs (e.g., social skills training, behavioral intervention, and therapeutic treatments), in-home respite (relief for family caregivers), supported living, supported employment, and work activity programs.[2, 4] Residential settings primarily include Intermediate Care Facilities (ICFs) and Community Care Facilities (CCFs), both providing care at various levels of need, as well as State Developmental Centers (SDCs), which are residential facilities providing habilitation and treatment.[5] The majority of consumers live and receive services in the community. In 2007, those receiving services resided in one of the following settings: with a family member or guardian (73%), a CCF (12%), an independent or supported living program (9%), a skilled nursing facility or ICF (4%), an SDC (1%), or another type of setting (1%).[6, 7]

Responsibility for implementation of the services authorized in the Lanterman Act is divided between the Department of Developmental Services (DDS) and twenty-one private, nonprofit Regional Centers (RCs).[1] The DDS system, which was allocated about $4.5 billion in the 2010–2011 state budget, currently serves more than 244,000 consumers. That number is expected to grow to nearly 252,000 consumers in the 2011–2012 fiscal year.[1, 8-10] In budget year 2009–2010, 52 percent of the RCs funding came directly through the state's

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general funds, with the remaining resources funded through a mixture of federal and state sources, as well other sources such as parental fees.[6, 11] The DDS acts as the budget intermediary with an oversight capacity, while the RCs are delegated the day-to-day responsibilities of determining diagnosis and eligibility, as well as carrying out the state's obligation to provide care to eligible individuals.[2, 12] The California Welfare and Institutions Code defines "developmental disability" as a disability that originated before the individual was eighteen years of age, continues or can be expected to continue indefinitely, and constitutes a substantial disability for the individual. To be eligible to receive DDS services, an individual must have been diagnosed by an RC or, if under three years old, must exhibit substantial developmental delay.[6]

Once eligibility is established, the RC conducts an individual planning process and develops an Individual Program Plan (IPP) or, for a consumer younger than three, an Individualized Family Service Plan (IFSP). This process involves setting specific goals and determining which services will best meet the individualized needs and preferences of the consumer. The RC then engages in service coordination to ensure that services in the IPP or IFSP are obtained. This can be either through generic agencies (publicly funded agencies that have a legal responsibility to serve all members of the general public – for example, Medi-Cal, County Department of Health, and In-Home Supportive Services), natural supports (family members or friends), or if no generic agency is available, through purchase of services from vendors using RC funding.[1, 6]

Among those consumers served in the community in 2007, about 78 percent received RC-funded services.[7] Services are provided to the consumer free of charge, with these exceptions: an income-based family cost participation requirement for individuals ages three to seventeen who are living at home and receiving respite, day care, or camp services; and family cost sharing for 24-hour out-of-home placement of children.[6]

The RC process of selecting vendors, referred to as "vendorization," consists of identification, selection, and utilization of service providers.[13] The Lanterman Act and Title 17 of the California Code of Regulations (Title 17, CCR) require that the vendorization process consider the following: (1) a provider's ability and past success in delivering quality services; (2) the existence of appropriate licensing, accreditation, and certifications; (3) the cost of providing services of comparable quality; and (4) the consumer's choice of provider.[7] Often, multiple vendors operate under a single business entity, as one entity receives multiple unique vendor numbers for each service type provided within each RC.[14] Of the 45,000 vendors who provide services, 40 percent are private nonprofits and for-profit agencies, and 60 percent are parents or other family members of DDS consumers.[6] Nonprofits are prevalent in the vendor community: among the 100 business entities with the highest level of total RC expenditures during fiscal year 2008, 51 percent were nonprofits, accounting for more than 1,130 vendors and over $466 million in purchased services.[14, 15] Vendors of supported employment programs are required by statute to have nonprofit status (Title 17, CCR §54351).

Challenges

The developmental disability service system faces two distinct types of challenges: (1) the increasing need for and cost of services, and (2) limited resources, rate freezes, and insufficient transparency in resource allocation.

Growing Needs and Costs

Growth in DDS Population Served in the Community

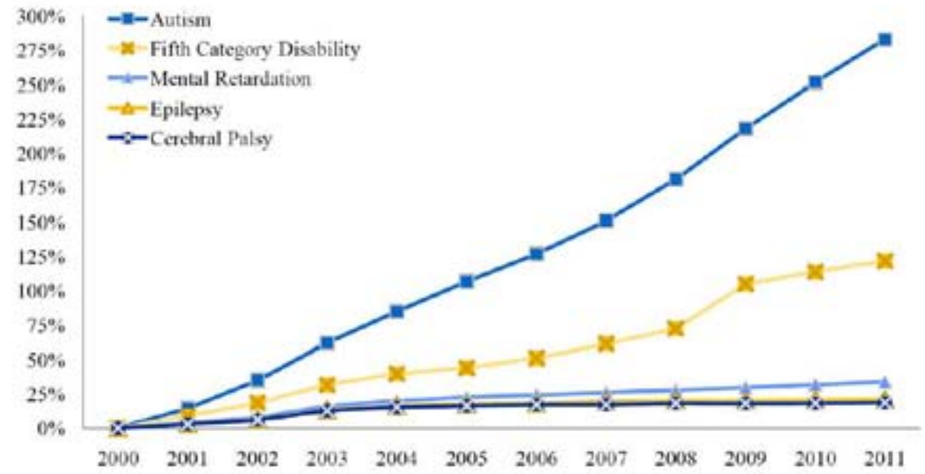
The overall number of DDS consumers has increased by 57 percent since 2000, while the general population of California has grown by only 14 percent during this same period.[8, 16] Specifically, the population of children under the age of three receiving early start services in the community has increased by 62 percent, and the population of DDS consumers over age three who are served in the community has increased by 53 percent.[8, 17, 18] The addition of new consumers accounts for 43 percent of the growth. However, the growth in the population served in the community, and the associated costs of such care were also impacted partially by the implementation of a planned closure of SDCs. The population of DDS consumers served in these facilities has decreased by 48 percent since 2000.[8] In 2007, the average per capita cost of care in SDCs was almost $276,000, compared to $16,165 in the community.[6] Moving SDC residents to community care settings accounted for 24 percent of RC expenditure growth between 2000 and 2007.[8]

Booming Autism Rates

Ongoing increases in the prevalence of individuals diagnosed with Autism Spectrum Disorders (ASD) have led the Centers for Disease Control and

Challenges to Sustaining California's Developmental Disability Services System, UCLA Center for Health Policy Research, March 2011

Exhibit 1. Growth in California population with autism versus three other major developmental disabilities and the "fifth category," 2000–2010



Notes: Developmental disability groups are not mutually exclusive, due to potential duplication of individuals across diagnostic categories. The "fifth category" refers to disability conditions found to be closely related to mental retardation or to require similar treatment (Welf. & Inst. Code §4512).

Source: Authors' analysis of data provided by Department of Developmental Services Data Extraction Unit, 2011.

Prevention (CDC) to declare ASD an urgent public health concern.[19] In California, the number of people with autism served by DDS has grown by 283 percent since 2000.[8] However, the annual growth rate has been steadily declining since 2003, indicating a potentially lower expected growth in the next decade. Since 2003, the incidence of other major developmental disabilities has also increased, among them: mental retardation (34%), epilepsy (21%), cerebral palsy (19%), and the "fifth category," representing conditions resembling mental retardation or requiring similar treatment (122%).[8] Additionally, the proportion of DDS consumers with higher needs due to dual diagnoses (mental illness and developmental disability) increased by 48 percent between 2001 and 2006.[8, 20]

Expenditures for individuals with autism are higher than those for individuals with any other type of developmental disability in every age group. In the provision of services to consumers with autism, the cost of serving children is lower than that of serving adults. The reason for this differential is that children are likely to live at home and use educational services paid for by school districts rather than by DDS, whereas adults have an increased need for community services or residential care.[7, 21] Specifically, in fiscal year 2006–2007, the average per capita cost of serving individuals with autism ages twenty-two to forty-one was 203 percent higher than the per capita cost for individuals with autism ages three to twenty-one (Exhibit 2).[7]

Aging of the Current DDS Population with Autism

The age composition of the DDS population diagnosed with autism is expected to shift in the coming years, affecting the cost of services. In 2007, 83 percent of the DDS population with autism was concentrated at ages three to twenty-one; 13 percent were ages twenty-two to forty-one; 4 percent were ages forty-two to sixty-one; and 0.2 percent were age sixty-two and older.[7] As the large proportion of individuals ages three to twenty-one transition to adulthood, DDS will face a substantial cost burden.[21] Because information is not readily available on the severity of the condition for each individual consumer, it is difficult to predict with precision the increased cost of DDS services as consumers age.

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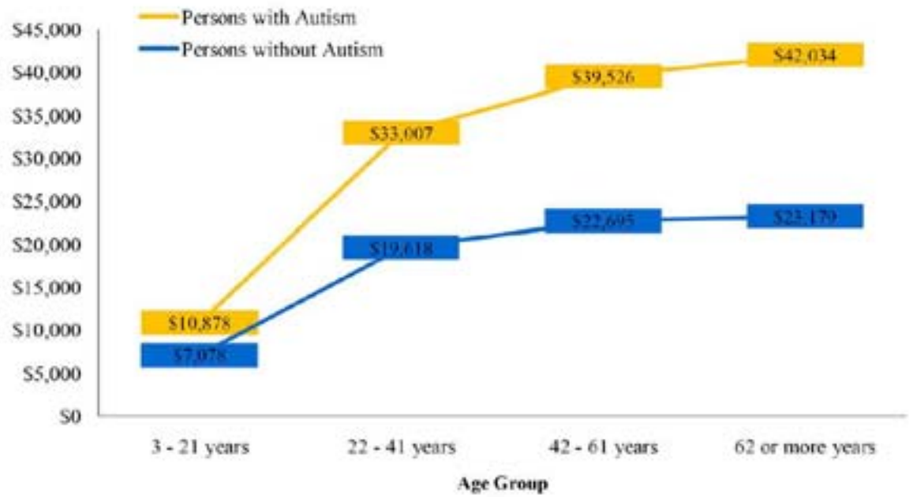
Exhibit 2. Average annual expenditure per consumer by age group for those with autism and those without, Fiscal Year 2006-2007



Source: Department of Developmental Services, *Fact book, 11th Edition*, 2008, State of California, Department of Developmental Services

Prolonged Life Expectancy of the Eligible Population and Aging of Informal Caregivers

Medical advances across the lifespan and improved health care have resulted in increased life expectancies among individuals with developmental disabilities. As a result, consumers require services for longer periods of time, as well as services at a higher intensity during their later years of life. Additionally, the aging of the eligible population is accompanied by the aging of their caregiving parents, leading to an increased level of need for supportive formal services. When a caregiver dies, a DDS consumer likely requires an alternative residential setting at a high cost.[6]

Limited Resources, Rate Freezes, and Insufficient Transparency in Resource Allocation

Recent Budgetary Cuts

The current state fiscal crisis further exacerbates DDS's increasing budgetary pressure, given the growing demands for care and the rising costs of that care. Although it has not yet been enacted, Governor Brown's budget currently proposes substantial reductions to the DDS system.[9, 22] As this policy note goes to press, budget discussions indicate a potential reduction of more than $500 million in the total budget available for developmental services, including a $174 million cut to be achieved through potential implementation of statewide purchase of service standards, among other cuts.[23] Additionally, it is proposed that current rate freezes be extended and vendor payment reduced by 4.5 percent through June 30, 2012.[10] Moreover, a 10 percent Medi-Cal rate cut is proposed, which will impact payments to vendors reimbursed via the Medi-Cal fee schedule.[24] Finally, the loss of federal matching funds will further reduce overall available funds.

Complex and Fragmented Rate Setting

The reimbursement rates for services provided by vendors are determined through differing rate-setting methodologies for different types of services, as stipulated in Title 17 CCR. Reimbursement rates may be based on a statute-defined rate, or they may be reached via a variety of cost-based methodologies, "usual and customary" rates, and rates negotiated between vendor and RC.[25, 29] The "usual and

customary rate" provision requires that rates reflect what is "regularly charged" by the vendor for the specified service to non-RC clients (Title 17, CCR §57210). In those cases where none of the above rate-setting processes is applicable, the vendor receives a negotiated rate from the vendoring regional center (Title 17, CCR §57300).

Insufficient Transparency and Accountability and Potential Non-Equitable Negotiated Rates

An amendment to the Lanterman Act passed in July 2009 established a requirement that RCs select the least costly available provider of a comparable service; the requirement to use cost-effective services is repeated in several parts of the act. However, the concepts of "cost-effectiveness" and "comparable services" are not defined in the statute, making it difficult to establish clear guidelines for vendor selection.[7, 8]

Additionally, RCs are charged with the authority and discretion to establish vendor payment rates for 96 of 155 active service codes, which account for almost half of total purchased services.[5] Should negotiations be required, the law and regulations do not mandate their format, content, or quality, nor do they require the RCs to document the negotiation process.[2] The California State Auditor has noted alarming examples of poor or nonexistent documentation of the RC rate-setting process, as well as cases of allegedly unethical rate-setting practices, failure to comply with Title 17 CCR regulations, and apparent disregard for the established rate freeze.[3] Lack of documentation may result in negotiated rates that may not be cost-effective and equitable.

Ongoing Rate Freezes

Since 2003, rates for many services have been frozen or restricted by the state, and on July 1, 2008, negotiated rates with all preexisting vendors were frozen.[5] Rates for new vendors established after that date are required to be less than or equal to the lower of either the statewide or regional average rate for the service type in question; once they have been set, these rates are also subject to the freeze.[2] Finally, existing law require that RCs reduce by 3% all vendor payments for services delivered between February 1, 2009, and June 30, 2010, and by 4.25% all vendor payments for services delivered between July 1, 2010, and June 30, 2011.[10] True operating costs of vendors are unknown, and current rates for some providers may not correspond with operating costs.

Can California Continue to Provide High-Quality and Cost-Effective Developmental Disability Services?

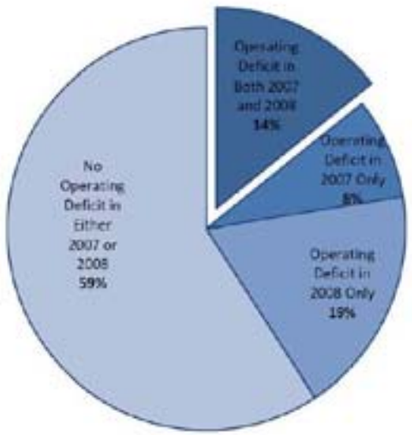
Potential Loss of Equitable Access to High-Quality Care

The continued financial health and operational capacity of RCs and their vendor network are necessary to the state's ability to provide high-quality services to individuals with developmental disabilities. Widespread rate freezes and payment reductions may ultimately harm vendors' financial viability. It has been shown that in response to increasing costs without corresponding rate increases, vendors offer lower pay to staff than do comparable employers. Given this competitive disadvantage, vendors struggle to recruit and retain direct-care staff, and newly hired staff often have less experience and lower levels of education than those whom they are replacing.[27]

Turnover among service providers is not predicted by low wages alone, but rather by a complex set of factors, including benefits such as paid time off and vacations.[28] The shortage of qualified direct-care personnel may impact the ability of providers to adequately meet the needs of service recipients.[27] The current frozen rate levels require vendors to absorb increasing implicit and explicit costs, thereby threatening vendors' financial solvency. Specifically, the rate freezes instituted in 2002 have neglected the 22 percent increase in implicit costs due strictly to inflation.[29]

Financial challenges that restrict the ability of nonprofits to operate as DDS service providers are of special concern, given their prevalence in the vendor community and their mandated involvement in providing supported employment. In some settings, such as nursing homes, nonprofit organizations have been shown to provide better quality care than for-profit facilities.[30, 31] To be consistent with their underlying mission to provide services to those in need, nonprofits are likely to offer services to any consumer, regardless of profitability. In contrast, for-profits are potentially able to risk-select consumers with lower perceived levels of need, or to minimize expenditures to maximize revenues.[31, 32] Among the 51 large nonprofits within the top 100 business entities in the DDS system in 2008, 16 (about 30%) reported an operating deficit, substantiating concern about their financial viability.[15] Such threats to the supply of services may fundamentally restrict consumer access and counteract the entitlement function of the Act.

Exhibit 3. Operating Deficits among the 51 Highest Expending Nonprofits in the DDS System, 2007 and 2008



Source: Authors' analysis of IRS Form 990 tax filings for 51 nonprofits within the 100 highest expending business entities in the DDS system in FY08, based on data generated by Department of Developmental Services Data Extraction Unit, January 2009.

Cost of Vendor Financial Insolvency to the State

Threatened financial insolvency of vendors, given rate freezes and inadequate reimbursement levels, may result in higher costs of care for the state. For example, Governor Brown's budget proposes a 10 percent rate cut for all Medi-Cal providers, including ICFs, beginning in June 2011. This rate cut would come on top of the 2009 freeze on reimbursement rates for these facilities.[26, 33] Almost 9,000 DDS consumers lived in skilled nursing facilities or ICFs in 2007.[7]

Some predictions suggest that as many as 5 percent of ICF beds will be lost as a result of rate cuts, requiring transfer of these consumers to other care facilities.[23] Should these consumers need to be transferred to SDCs, which are more costly to the state, a portion of the savings achieved by reducing the SDC population over the last decade may be lost. The annual per capita cost of care is about $70,000 for individuals residing in ICFs, compared to almost $276,000 for those in SDCs.[6, 34] Although half of the cost of care in both settings is offset by federal reimbursement, the increased cost to the state would be significant.

Policy Recommendations

Based on our analysis of the challenges facing the California developmental disability services system, we propose the following policy recommendations to ensure both adequate and equitable access to high-quality, cost-effective services throughout California.

Adjust Frozen Rates to Ensure Vendors' Financial Viability and Continued Access to Care

Establishing a fee schedule that is informed by thorough cost-based analysis and that incorporates adjustments for the increasing cost of service provision would allow vendors to sustainably maintain operations by limiting undue fiscal strain. A cost-based analysis recognizes the inherent variability in consumer needs -- where more severe conditions require more intense and expensive services -- and it also engages stakeholders in the rate-setting process.

Furthermore, the cost statements required for rate-setting should reflect the true costs of providing efficient and high-quality services, as required by the California Welfare and Institutions Code §4690. This would allow for the consideration of any mechanisms that have been employed by vendors to reduce costs in a rate-restricted environment in order to maintain solvency. The inclusion of an explicit adjustment for input price inflation, such as the Consumer Price Index (CPI), would mitigate threats to access by recognizing the ongoing cost increases faced by vendors.

Adopt Equitable and Transparent Vendor Payment Systems

Promote Transparency and Accountability

The California State Auditor's report of 2010 recommended establishing a uniform and transparent rate-setting process to improve cost effectiveness; that recommendation resulted in initial efforts by the DDS to implement reforms. However, the scope of the reforms focuses on a directive requiring RCs to "document how they determine that the rates they negotiate or otherwise establish are reasonable for the services to be provided."[2] Additional efforts to increase transparency in vendor selection and vendor payment are needed, and oversight of the process at every level should be increased.[2] For negotiated rates to properly demonstrate cost-effectiveness, standard definitions of the terms "cost-effective" and "comparable services" should be developed.[7] A clear, uniform definition of

Challenges to Sustaining California's Developmental Disability Services System, UCLA Center for Health Policy Research, March 2011

these terms will facilitate clear guidelines of vendor selection.[2, 5]

Extend Comprehensive Vendor Cost Reporting Requirements to All Service Types

Standardized, comprehensive reporting of finances and utilization by both vendors and RCs will lay the groundwork for a more efficient, cost-effective, and transparent system. One of the major obstacles to reconciling the cost of services with shrinking budgets is the lack of detailed data on current costs for service types that at present do not require cost reporting. Enhanced reporting can support appropriate cost-based reimbursements, such as those implemented by the Federally Qualified Health Center (FQHC) program.[28] A comprehensive cost-reporting mechanism to inform RC budget processes and rate-setting negotiations can facilitate transparent evaluations of vendor and service sustainability, as well as reduce variability and inequity in vendor payments. In the setting of a severe budget deficit statewide, cost documentation would be valuable in informing difficult state budgetary decisions.

Implement a Standard Negotiated Rate System

A standard rate system for services that currently do not have a particular rate-setting method, such as transportation and behavioral services, would promote equity between vendors and service codes, limit wasteful spending, and protect vendors with less financial resiliency, including nonprofits and the parents of consumers.

Maximize System Efficiency

Develop Efficient Service Provision

Conducting real-time reviews of opportunities to minimize the marginal costs of additional DDS consumers and to eliminate inefficient service selection, without compromising the quality of care, could assuage the reduction in overall funding. For instance, if group-setting care can be demonstrated to be as effective as individual-setting care, RC strategies should maximize group service provision.[4] Additionally, establishing a more competitive bidding process for vendor selection or a "preferred provider" system might enhance efficiency.[5]

Governor Brown's proposed trailer bill language for the 2011–2012 budget discusses the establishment of statewide purchase-of-services standards in lieu of the independent standards currently decided at the RC level.[22] The development of such standards should be done in the context of a careful examination of successful mechanisms that promote the delivery of high-quality equitable services rather than in the context of budget reduction efforts. Such standards should not be utilized to impose artificial caps on reimbursement rates, to eliminate service, or to limit the flexibility or the availability of appropriate services and supports as determined in the IPP.

Identify and Use Additional Funding Sources

Sources of additional funding outside of the DDS budget should be maximized. Existing regulations require RCs to use generic services before purchasing services, but a clear methodology ensuring compliance is lacking.[9] Additionally, federal Medicaid reimbursement should be maximized in a number of DDS service areas, including the Home and Community–Based Services (HCBS) Waiver.[35] The state has undertaken some efforts to enhance federal reimbursement, such as increasing the enrollment cap under the HCBS waiver in 2008.[9] However, in 2007, as many as 1,100 consumers were being served in facilities that were not eligible for waiver participation, representing a lost opportunity for federal reimbursement of as much as $10.7 million.[6, 35] Further benefit can be gained by ensuring service coordination with private insurance plans to prevent duplication of benefits.[36] Finally, it has been suggested that the family cost-participation plan, currently in place for a small number of services, should be expanded to include additional services.[6, 9] However given the very high cost of the vital services required by many of the individuals served by DDS, it is essential that income levels or other qualifying criteria be carefully evaluated to prevent catastrophic financial consequences for families.

Conclusion

California's DDS system faces considerable challenges due to rate freezes that have extended for more than a decade, despite ongoing growth in both the demand for services and in the underlying costs of providing services. The policy recommendations presented above suggest that the legislature and governor need to give serious consideration to finding additional solutions to these challenges.

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Acknowledgments

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Challenges to Sustaining California's Developmental Disability Services System, UCLA Center for Health Policy Research, March 2011

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29th Legislative Breakfast
North Los Angeles County Regional Center

Tierra del Sol Board Member
Karren McClenahan

Karren McClenahan and her husband Patrick are the proud parents of Eric and Kelly.

When Kelly was born 27 years ago, Karren recognized that one important aspect of her role as mom would be to make sure that Kelly's special needs for physical, medical and educational services, would not prevent her from growing up as a happy, thriving and loved member of her family. This is the balancing act that all special needs families perform each and every day.

Now, as a young adult, Kelly is a joyous part of every aspect of her family life at home with her mother and father, and with her large and loving extended family of grandparents, her brother and sister-in-law. And beyond her family, Kelly is a valued member of her church and her learning community at Tierra del Sol.

While Karren and Patrick have succeeded in raising Kelly, they know they have had help along the way. There are unique needs that Kelly has that no family could possibly handle all by themselves. They are very grateful for the special education, and Regional Center services that have assisted them along the way. Without this support, Kelly's needs could overwhelm any family. But, in partnership, Kelly has had the opportunity to have productive life experiences and social relationships, and to have a life of her own as she grows into a beautiful young woman.

When school years gave way to young adulthood, Karren became even more aware of the role community-based adult programs play in the lives of people with developmental disabilities and their families. Karren first became involved with Tierra del Sol as a new and appreciative parent. She soon realized that the true heart, soul and backbone of the life-long supports Kelly will need are the direct support professionals that are employed, coordinated and supervised by community organizations like Tierra del Sol. She also learned that these organizations are severely limited in the wages they can pay to direct support staff due to low reimbursement rates. She learned that many staff members leave their full-time jobs at Tierra only to rush to a second job in order to earn enough to live on.

Tierra del Sol Board Member
Karren McClenahan

At that point Karren became fully engaged. She joined Tierra del Sol's Board of Directors, where she quickly became a leading voice and force in support of Tierra's workforce. Karren now leads many of Tierra del Sol's volunteer efforts to engage all of its families in the important work of supporting our direct support professionals and raising the precious funds the organization needs to make up for the growing gap between regional center reimbursements, and the true costs of providing critical services.

Karren knows that Kelly is blessed to have a loving family and a strong community-based support system. She has dedicated herself to working to ensure that the unsung heroes in the lives of all special needs families -- those men and women who provide direct support each and every day, are not forgotten. Without them all of our progress and hopes for the future would be lost.

The Adult Skills Center (TASC)
Board Member *Nick Leone*

I would like to thank the North Los Angeles County Regional Center for giving me the opportunity to address our honored Legislative leaders, the Regional Center staff and the Regional Center consumers here today.

My wife and I are both retired LAUSD teachers, with a total of 71 years of teaching experience, but more importantly, we are the parents of Nick, a 31-year-old Regional Center consumer. I'd like to invite you to join us on a brief trip through his and our journey.

This journey begins on November 8, 1982 and travels through time to this day:
After what appeared to be a typical pregnancy, just 3 weeks shy of the 40 week norm,

Nick was born – 5 pounds, 8 ounces and 19 inches "tall". His Apgars were good, 8 and 9 on the 10 point scale. Three days later, just before getting ready to go home, he stopped breathing – unknown reasons, but later stated as "low blood sugar". Within a few minutes, which felt like an hour, he was being resuscitated. Afterward he spent 9 long days in the Cedar Sinai's Neonatal ICU. The next three-plus years flew, maybe crawled, by, with many early childhood milestones missed. Finally, by age 4, he was assessed by the Regional Center and found eligible due to Cerebral Palsy.

Thanks to the many supports provided through DDS and Regional Center vendors, Nick has been able to overcome many obstacles due to his physical and intellectual issues. Early Intervention Preschool classes enabled him to improve his speech and language skills. Sensory Integration Therapy classes at Glendale Adventist Hospital helped him deal with coordination, spatial awareness, and balance. Ahead with Horses, a vaulting and gymnastics program on horseback, improved his gross motor skills and gave him the confidence that he could do almost anything. Special Education, Adapted P.E, dance, and drama classes in elementary, middle, and high school furthered his overall development. Then, in 2001, after completing 4 challenging years of high school, he entered The Adult Skills Center's Day Program for 2 ½ years. While there he developed critical transition skills that allowed him to improve his peer interactions and basic job skills. During this time he also spent two, 12-week summer periods in full-leg casts due to foot surgeries to correct congenital defects, and also had surgeries to straighten all 10 hammered-toes.

The Adult Skills Center (TASC)
Board Member *Nick Leone*

All of these efforts, combined, enabled Nick to find and successfully keep a job at Mann/ Regency Theatres since December 2003, with the assistance from a Job Coaching and community-based program at Jay Nolan Services. He has also been doing background acting on an FX television sitcom, called "Legit", which deals with many disability issues through the rather edgy, but lovingly direct sense of humor of standup comedian and actor Jim Jefferies!

Although Nick was quite small at birth, he has grown into a substantial young man. From the 5 pound, 8 ounce, 19" newborn, he's become a 213 pound, 6'8" guy, with size 15 shoes! One final detail, just 8 months ago he joined the "Zipper Club". Yes, open chest, heart surgery! The whole "nine yards", actually, just about 12 inches! Good news, he's doing well. So, a new chapter in his journey has begun, but we'll need to save all for that another time.

It must be noted that through thick and thin economic times Regional Center's service coordinators and their vendored providers have been there for us. Caring administrators and knowledgeable staffs were willing to accept pay cuts and forgo pay raises since 2008. Having been public school teachers, my wife and I recognize their motivation and applaud their dedication. As a Board of Directors Member at TASC, since 2001, and TASC's Board Treasurer for the last five years, I, too, know the financial struggles that have faced these vendors, their staffs, their consumers, and their families.

It was just 45 years ago that the Lanterman Act established the right of qualified individuals to receive treatment, habilitation services, and supports in the least restrictive environment. These services must meet the needs and choices of each person, regardless of age or degree of disability, or stage of life, and must support their integration into the mainstream life of their community.

This Act also defines a basic corresponding obligation; the obligation which it imposes on our State to provide such services. DDS, Regional Center and their vendored service providers need and require our support. Please, let's all work to make that happen!

Sincerely,
Nicholas Leone

New Horizons' Direct Support Professional *Sarah Macon*

Having worked in the field of Social Services since 1984, Sarah Macon has been employed at New Horizons for three and a half years as a CNA Instructor in the Achievement Center's Center Based and Personal Cooking Classes. Aside from her duties in the classroom, Sarah also serves as the agency's Brite Lites Coordinator. She teaches clients who are members of the group dance routines and songs which they later perform on the campus of New Horizons and in the community.

Sarah began her current career as a volunteer at Camarillo State Hospital in 1983. While there she worked with geriatric patients, children and adolescents, Alzheimer's patients, and individuals with behavioral disabilities. It was here that she discovered her passion for working in social services.

Sarah is a single mom of three girls. She, like many direct support professionals, must work two jobs in order to provide for her family. Over the years she sometimes has had to work three jobs just to make "ends meet". After barely meeting rent, groceries, and gas to get to and from work, there usually is nothing left. She has not been able to save for college for her daughters or "those extra special things" that are needed on occasion. In order to maintain her current residence, Sarah's oldest daughter continues to live at the family home because her daughter's part-time job helps cover the monthly rent. A financial sacrifice Sarah wishes she could change.

Life at times has been a complete struggle for Sarah. The guilt of not being able to spend time with her girls over the years has been tough. The schedule of going to work in the morning, evening, and weekends has taken its toll on Sarah. Who often ask, "I do a very important job caring for and teaching people with disabilities, why am I not able to make a living off of it without a struggle?"

Today, when not at New Horizons, Sarah continues to work two part-time jobs with disabled adults as a DSP. When asked if she will leave the field, Sarah says she thinks of it often, especially to be able to provide for her family. Sarah shared that what keeps her working as a DSP is the people she cares for are like her second family. She really enjoys taking her group home residents of her second job to church service every Sunday morning.

Economic Policy Institute's Family Budget

Economic Policy Institute's Family Budget

Economic Policy Institute's Family Budget Calculator measures the income a family needs in order to attain a secure yet modest living standard by estimating community-specific costs of housing, food, child care, transportation, health care, other necessities, and taxes. The budgets, updated for 2013, are calculated for 615 U.S. communities and six family types (either one or two parents with one, two, or three children).

As compared with official poverty thresholds such as the federal poverty line and Supplemental Poverty Measure, EPI's family budgets offer a higher degree of geographic customization and provide a more accurate measure of economic security. In all cases, they show families need more than twice the amount of the federal poverty line to get by.

MONTHLY COSTS
for a family with
1 parent *and* **1 child**
in Los Angeles-Long Beach, California

HOUSING	$1,421
FOOD	$369
CHILD CARE	$720
TRANSPORTATION	$450
HEALTH CARE	$1,009
OTHER NECESSITIES	$458
TAXES	$660
MONTHLY TOTAL	$5,086
ANNUAL TOTAL	$61,037

MONTHLY COSTS
for a family with
2 parents *and* **2 children**
in Los Angeles-Long Beach, California

HOUSING	$1,421
FOOD	$754
CHILD CARE	$953
TRANSPORTATION	$577
HEALTH CARE	$1,573
OTHER NECESSITIES	$557
TAXES	$382
MONTHLY TOTAL	$6,217
ANNUAL TOTAL	$74,605

Economic Policy Institute - www.epi.org

Entry Level Wage Comparison

Entry Level Wage Comparison

For a Service Provider staff person with 1 child, an individual would earn just 28% of the annual salary needed to attain a secure yet modest living standard based on the Economic Policy Institute's Family Budget Calculator. A 353% pay increase would be required to reach the minimum wage needed to sustain a family's needs.

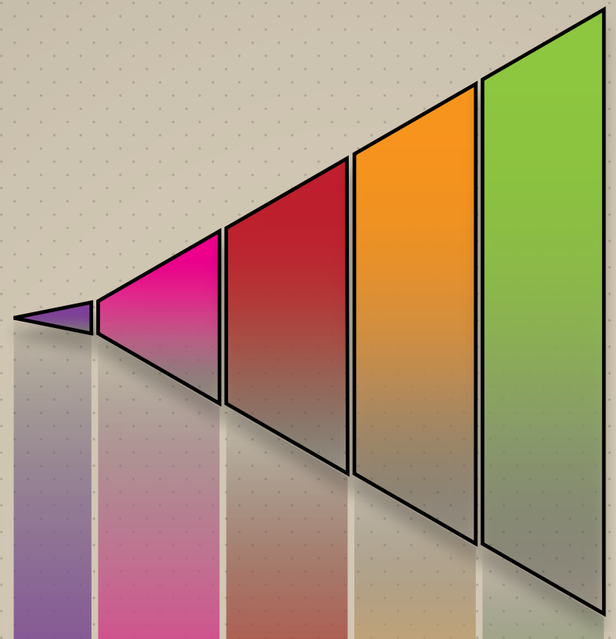
	Hourly Wage	Monthly	Yearly
Service Provider Staff	$9.00	$1,440	$17,280
Walmart Employee	$9.45	$1,512	$18,144
CA State Custodian*	$13.00	$2,098	$25,176
Fairview DC Laundry Worker**	$14.36	$2,297	$27,564
Fairview DC Groundskeeper**	$16.79	$2,687	$32,244

* http://www.calhr.ca.gov/state-hr-professionals/pages/pay-scales.aspx
** http://www.dds.ca.gov/JobBulletin/index.cfm

Voting Population

Potential NLACRC Voting Population

North Los Angeles County Regional Center ("NLACRC") has a large potential voting population. The NLACRC community includes people with developmental disabilities ("consumers"), their family members, vendors and their employees, NLACRC staff and their families. Social media also has the potential to make an impact. In a close election such as the race that was held in 2013 to fill the 45th District Assemblymember seat vacancy, our votes can make a difference.



Social Media
Difficult to quantify, but can have an impact.

Family Members (AVG. 2.55*) 53,142
Consumer Family Members 52,163
NLACRC Family Members 979

Consumers 20,840
Consumers 20,840

Vendors & Their Employees** 5,569

North Los Angeles County Regional Center Staff 384
Staff 384

*According to the US Census Bureau, the average population per household is 2.55.
**The 5,569 number represents a Coalition of Service Providers which includes 26 vendors who serve consumers in the NLACRC catchment area, and their employees. NLACRC works with over 1,200 vendors and their employees which makes the potential vendor voting population much higher.

Other Resources

Inadequate Rates for Service Provision in California
http://arcanet.org/wp-content/uploads/2014/02/Inadequate-Rates-for-Service-Provision-in-California.pdf

Proposal from the Lanterman Coalition on the California Budget and keeping the Promise to Californians with Developmental Disabilities
http://arcanet.org/wp-content/uploads/2014/03/lanterman-coalition-budget-proposal.pdf

Association of Regional Centers (ARCA) Position Statement
Governor's Proposed Budget for Fiscal Year 2014-15
http://arcanet.org/blog/press-room/revised-budget-position/

Letter That You Can Send to Legislators

This format can be used to write a letter to legislators. Please keep it to one page.

Date

Honorable (first and last name of legislator)
(Title & District)
State Capitol
Sacramento, CA Zip Code

Dear (Title & Last Name – for example, Assembly Member Smith):

My name is _____ and I am a _____ (consumer / family member / service provider / advocate).

The safety net of direct support professionals is at high risk due to low wages, high turnover rates and increasing costs to service providers. I urge you to increase rates paid to regional center service providers by 5% annually beginning in fiscal year 2014-15. This will help to restore the many years of budget reductions until a longer-term solution can be developed and implemented.

(Share a personal story here about why the services and support that you or your family member receive from a direct support professional is important. Please keep it brief).

Please help to ensure the well-being and safety of more than 270,000 Californians with developmental disabilities. The future of our state's most vulnerable citizens is in your hands.

Sincerely,
SIGN YOUR NAME

Print your name
Street Address
City, State, Zip Code

CA STATE SENATORS

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Fax (202) 228-4056
e-mail: http://www.boxer.senate.gov/en/contact/policycomments.cfm

(elected 1993)

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(elected 1992)

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(elected A. 2012; term limit 2024)

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(elected: Spec Elec. A. 6/2010; term limit 2016)

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(elected: A. 2013 in special election; term limit 2024)

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(elected: A. 2012; term limit 2024)

2014 Legislators

CA ASSEMBLY MEMBERS (continued)

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(elected: A. 2012; term limit: 2024)

Note:
- Assembly members are limited to three 2-year terms (6 years total).
- Senators are limited to 2 4-year terms (8 years total).

As of 6/5/2012, newly elected legislators can serve up to 12 years either in the California State Senate or State Assembly.

CA CONGRESSIONAL REPRESENTATIVES

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(elected 1992)

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(elected 2000)

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(elected 2012)

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(elected 1996)

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(elected 1974)

L.A. CITY COUNCIL

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2014 Legislators

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2014 Legislators

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(elected 2013)

CA GOVERNOR

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Governor of California
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(elected 2010)

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President of the United States
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(elected 2008 & 2012)

LEGISLATIVE BREAKFAST 2014 ACKNOWLEDGMENTS

Thank you to our legislators and their staff for their participation at the 29th Jynny Retzinger Legislative Breakfast, and for your continued commitment and support.

Legislative Breakfast Planning Committee:
Diane Ambrose, Jessica Gould, Sara Iwahashi, Duane Joslin, Michele Marra, Steve Miller, Jennifer Pecor, George Stevens, Tavia Wooley

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And a very special thank you to everyone in attendance at this year's breakfast.
See you next year!

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